Justifications for Continuous Sedation until Death (running head)

Continuous Sedation until Death: Moral Justifications of Physicians and Nurses

A Content Analysis of Opinion Pieces (title)

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Sam Rys, RN, MSc [1,2 *]

Freddy Mortier, MA, PhD [2,3]

Luc Deliens, MA, MSc, PhD [2,4]

Reginald Deschepper, MA, PhD [1,2]

Margaret Pabst Battin, MFA, PhD [5]

Johan Bilsen, RN, MSc, PhD [1,2]

[1] Department of Public Health, Vrije Universiteit Brussel, Brussels, Belgium

[2] End-of-Life Care Research Group, Ghent University & Vrije Universiteit Brussel, Brussels, Belgium

[3] Bioethics Institute Ghent, Ghent University, Ghent, Belgium

[4] Department of Public and Occupational Health, EMGO Institute for Health and Care Research, Expertise Centre for Palliative Care, VU University Medical Center, Amsterdam, the Netherlands

[5] Department of Philosophy, University of Utah, Salt Lake City, UT, USA

* Corresponding author:

Sam Rys

Department of Public Health

Faculty of Medicine and Pharmacy

Vrije Universiteit Brussel

Laarbeeklaan 103

1090 Brussel

BELGIUM

Tel 0032 2 477 47 06

Fax 0032 2 477 42 19

samrys@vub.ac.be

Continuous Sedation until Death: Moral Justifications of Physicians and Nurses

A Content Analysis of Opinion Pieces

ABSTRACT

Continuous Sedation until Death (CSD), the act of reducing or removing the consciousness of an incurably ill patient until death, often provokes medical-ethical discussions in the opinion sections of medical and nursing journals. A content analysis of opinion pieces in medical and nursing literature was conducted to examine how clinicians define and describe CSD, and how they justify this practice morally. Most publications were written by physicians and published in palliative or general medicine journals. *Terminal Sedation* and *Palliative Sedation* are the most frequently used terms to describe CSD. Seventeen definitions with varying content were identified. Continuous Sedation until Death was found to be morally justified in 73% of the publications using justifications such as Last Resort, Doctrine of Double Effect, Sanctity of Life, Autonomy, and Proportionality. The debate over CSD in the opinion sections of medical and nursing journals lacks uniform terms and definitions, and is profoundly marked by 'charged language', aiming at realizing agreement in attitude towards CSD. Not all of the moral justifications found are equally straightforward. To enable a more effective debate, the terms, definitions and justifications for CSD need to be further clarified.

Keywords: Terminal Sedation, Palliative Sedation, Deep Sedation, Content Analysis, Opinions, Palliative Care, Terminal Care

INTRODUCTION

Sedating a terminally ill patient to relieve distress has been a prevalent practice in end-of-life care a considerable time (Ventafridda et al., 1990; Miccinesi et al., 2006). This sedation can be used for short periods (intermittently) or continuously until death, and the depth of sedation can vary from a lower level of consciousness to unconsciousness. In this study we focus on the practice of *Continuous Sedation until Death* (CSD), the act of reducing or removing the consciousness of an incurably ill patient until death.

As CSD has become part of common medial practice, it has also turned into a very relevant topic in medical-ethical discussions (van Delden, 2007). Research in Belgium and the Netherlands has demonstrated that this far-reaching treatment is increasingly being used in end-of-life care (Chambaere et al., 2010; Rietjens et al., 2008). Although these (and other) self-report surveys indicate that CSD is appropriately applied in most cases, a substantial number of physicians in these studies declared to have used CSD with a (co-)intention to hasten death (Chambaere et al., 2010; Rietjens et al., 2004; Swart et al., 2010; Van Deijck et al., 2010). Some of these studies also indicate that an informed consent of the patient is frequently lacking and, in 8% of the cases in the Belgian study, alternatives to CSD had been possible to control suffering.

To promote a good practice of CSD, several guidelines (or position statements) on this intervention have been published (Braun et al., 2003; de Graeff and Dean, 2007; Hawryluck et al., 2002; Morita et al., 2005; National Ethics Committee, 2006; Council on Ethical and Judicial Affairs, 2008; Kirk and Mahon, 2010; Cherny and Radbruch, 2009; Committee on National Guideline for Palliative Sedation RDMA, 2009; Broeckaert et al., 2010). By formulating recommendations, these guidelines define the circumstances under which CSD can be considered morally justified. Moreover, the terms and definitions for CSD that are used in these guidelines can be considered part and parcel of attempts to define the conditions under which the practice of CSD is justified, e.g. by emphasizing the palliative intention in the term or definition for CSD.

Guidelines are usually a result of well thought-out (and frequently top-down) processes, in which specialist physicians, lawyers, ethicists, and perhaps other experts are involved. Such documents are

not necessarily reflective of the moral considerations of practicing physicians or nurses. Conversely, the opinion sections of medical and nursing journals offer a chance to publish their considerations on the matter, and may therefore provide a representation that is closer to the diverse views and experiences of clinicians in the field. Because we are particularly interested in the (moral) reasonings of professionals who are regularly confronted with dying patients and practices such as CSD, we decided to conduct a content analysis of opinion pieces published in medical and nursing journals to examine how clinicians define and describe CSD, and how they morally justify this practice.

METHODS

The content analysis focused exclusively on English editorials, comments, and letters that are indexed in MEDLINE/PubMed or CINAHL (1966 to November 2009). Our purpose here was to open up both the medical as well as the nursing literature. From here on, we will refer to these three publication types by using the term 'opinion piece'. The following criteria were used to determine 'opinion pieces on CSD':

Inclusion criteria (both criteria must be met):

- The publication is indexed as an editorial, a comment, or a letter to the editor.
- The publication discusses CSD; the act of reducing or removing the consciousness of an incurably ill patient until death.

Exclusion criteria:

- Research letters. These publications ought to be neutral; they primarily focus on presenting scientific data, not on formulating opinions.
- Publications containing only methodological critique on research
- Purely clinical or pharmacological publications

In order to identify and gather the desired opinion pieces, the CINAHL and PubMed search engines were used by means of a sensitive (regarding content) and specific (regarding publication type) search filter (see appendix). This automated search yielded 369 results in PubMed (on November 9, 2009) and 122 in CINAHL (on November 5, 2009). Following the inclusion criteria and after checking for duplicate publications, 89 publications were kept for analysis.

All included publications were read several times by one researcher (SR). During this reading process, a codebook was developed to encode the general characteristics and the embedded information of the opinion pieces. Encoding general information and characteristics –such as author or journal characteristics, terms and definitions used for CSD- proved to be obvious. Journals were considered as a palliative care journal when they explicitly declared themselves to be connected with palliative care, either in their title or their mission statement (Hermsen and ten Have, 2001). The same reasoning was applied to determine bioethical journals. Journals that are listed in the 'general and internal medicine' category of the ISI Web of Knowledge were classified as such. A few journals proclaim to be connected with palliative care but are also listed in the general and internal medicine category, for example *The Journal of Pain and Symptom Management*. Such journals are considered in this study as palliative care journals.

In order to categorize the observed moral justifications, specific coding instructions needed to be developed. Therefore, in consultation with three researchers –an anthropologist (RD), an ethicist (FM), and a health scientist (SR)- an inductive coding framework of moral justifications was developed by analyzing a random sample of the selected publications through an open coding method (Strauss and Corbin, 1990). By comparing and grouping text extracts from the opinion pieces, main categories of justifications were induced. These categories were then labeled using existing (ethical) concepts such as Doctrine of Double Effect, Autonomy, etc. For each category, corresponding text indicators were made explicit to facilitate the further coding process. In addition, the option was left open to encode other justifications that could not be classified within any of these five types of justifications. This inductive framework acted thus as a coding instrument, but is also a result of this study.

The selected publications were subsequently encoded by one researcher (SR). In order to check the quality of this coding, a random sample of ten opinion pieces with moral justifications was also coded by two other researchers (FM and RD) working independent of each other. The inter-rater agreement for this sample was good with a Siegel and Castellan's kappa score of 0.75. Differences in coding were discussed until consensus was reached. All the encoded data were entered in a SPSS file in order to perform the descriptive analyses (SPSS Inc., Chicago, IL).

RESULTS

In total, 89 opinion pieces on CSD were found. The majority of these publications (80.9%) consist of comments or letters from readers, while only 19% were written by an editor (table 1). Approximately 40% of the opinion pieces were published in palliative care journals, while 38.2% were published in general and internal medicine journals. Six opinion pieces were published in bioethical journals and 13 were published in other journals, such as oncology journals (6 publications) or nursing journals (4 publications). Seventy-six point four percent of the opinion pieces were written by a physician, 11.2% by a nurse, and 4.5% by an ethicist or philosopher. Most of the authors (65.2%) work in North America (USA 59.6%, Canada 5.6%), whereas 22.5% are employed in Europe (UK 12.4%, the Netherlands 6.7%). In 19.1% of the publications, a definition of CSD could be distinguished and in 73% at least one moral justification for CSD could be identified.

The number of publications per year is shown in table 2. In our sample the first opinion piece on CSD was published in 1993; all the other opinion pieces have been published since 1996. Looking at the total number of opinion pieces per publication year shows that since 2000 there has been an increasing attention for CSD. Table 2 also shows a historical trend in the terms used to describe CSD. *Terminal Sedation* is the term most used (38 publications), followed by *Palliative Sedation* (27 publications). Other terms commonly used are *Sedation* (n=11), *Slow Euthanasia* (n=5), and *Sedation in the Imminently Dying* (n=4). Although *Palliative Sedation* is the second most frequently used term, its first time use as the preferred term for CSD in an opinion piece only dates from 2000.

Definitions of CSD were found in 17 publications and referred to 4 different terms for CSD, namely *Terminal Sedation*, *Palliative Sedation*, *Sedation,* and *Slow Euthanasia* (table 3). The three most commonly used core elements of all definitions are ‘Removing consciousness’, ‘Refractory symptoms’, and ‘Lowering consciousness by titrating sedatives’. *Terminal Sedation* seems to be more connected to the core element ‘Removing consciousness’ (44.4%), whereas the term *Palliative Sedation* rather seems to refer to the element ‘Refractory symptoms’ (66.7%). Three definitions of the term *Terminal Sedation* include withholding of Artificial Nutrition and Hydration (ANH) as part of the definition. Three definitions refer to the Doctrine of Double Effect, by stating that the intention of CSD is to control symptoms and not to cause death.

Five types of moral justifications for CSD were identified by using the constant comparative method. These types were labelled as follows: Last Resort, Doctrine of Double Effect, Sanctity of Life, Autonomy, and Proportionality. Box 1 gives a general explanation of these categories of justifications and sums up the corresponding text indicators, as well as some text examples from the selected publications.

In general, CSD is found to be morally justified in 65 of all the 89 publications (table 4). Justifications labelled as 'Last Resort' were found in 75.4% of these 65 publications, Double Effect reasoning in 52.3%. 'Sanctity of Life' serves as a justification in 33.8%, 'Autonomy' and 'Proportionality' in 32.3%. One publication presented the 'Principle of Collaboration' as a moral justification, while another opinion piece mentioned avoiding extreme bereavement for the family. The issue whether ANH should be withheld in combination with CSD was also taken into account when researching the justifications for CSD. In most publications, it is not clear if the possible (moral) problems regarding ANH are included when authors justify the practice of CSD. In fact, there were only 14 publications where the withholding of ANH is also found to be justified. In 9 opinion pieces the issue of ANH is explicitly excluded in the justification and in 5 of these 9 publications, separate justifications for the withholding of ANH are given (not shown in table).

DISCUSSION

Opinion pieces on Continuous Sedation until Death (CSD) in medical and nursing literature are mostly published in the form of comments or letters to the editor and written principally by physicians in the USA or the UK. Palliative journals publish relatively more opinions on CSD than other types of journals and, in general, most opinion pieces have been published since 2000. Uniform terms and definitions for CSD are lacking in the opinion sections of medical and nursing journals. CSD was found to be morally justified in more than seventy percent of the publications. After a thorough analysis, the found justifications can be categorized in the following types: Last Resort, Doctrine of Double Effect, Sanctity of Life, Autonomy, and Proportionality.

By conducting a content analysis of opinion pieces on CSD, we were able to gain insight into the (moral) considerations of clinicians in the field on this practice –although it must be noted that

clinicians who write opinion pieces are possibly more academically oriented than the average clinician. The content analysis deduced a framework of moral justifications that are frequently used by clinicians to justify CSD. This framework as well as its coding instructions proved to have a good inter-rater reliability. Other types of publications or publication channels, such as gray literature, may have included different views on the topic, but exploring them was beyond the scope of this study. With the exception of a few short quotations of moral justifications for CSD, it was not possible to present a detailed account of the opinion pieces. Some authors' insights are more extensive than the text examples shown in box 1. Another limitation is that the content analysis is limited to opinion pieces published in English.

Given the found terms and justifications, our content analysis clearly shows that CSD was introduced as a controversial topic in the opinion sections of medical and nursing journals. In 1996, Billings and Block argued in their opinion piece 'Slow Euthanasia' that CSD can be considered as a form of euthanasia (Billings and Block, 1996). Others disputed this and emphasized that practices such as euthanasia do not represent appropriate extensions of palliative care (Mount, 1996). These and other publications have thus instigated a debate in scientific journals about how CSD should be considered and practiced. Therefore, the debate on CSD in medical and nursing literature is highly influenced by societal concerns, rather than being driven solely by scientific (clinical) evidence. Additionally, the current (clinical) evidence regarding CSD is relatively sparse. A recent review of the research literature identified a number of important gaps in the knowledge on CSD. These gaps include knowledge of the (possible life-shortening) effects of sedation, the combination of CSD with the withholding of ANH, and information on the decision-making process (Claessens et al., 2008). Despite this lack of evidence, a range of opinions on CSD has been formulated and published in the opinion sections of scientific journals. Moreover, in the majority of the reviewed publications, CSD is found to be morally justified. Given this context, it is interesting to further examine how this debate is being carried out.

It is striking that different terms for CSD are used, and, further, that some terms are construed in such a way they match the stance of the author on justifiability. The distribution of the terms 'palliative' and 'terminal' sedation throughout the various opinion pieces shows a struggle over the emotive meanings of the words used in discussing CSD. Terms such as 'palliative' or 'terminal' have different so-called

(by Stevenson) emotive meanings. The emotive meaning of a term refers to its affectivity in respect to the attitude of the listener or reader (Stevenson, 1969). This is contrasted to the descriptive meaning of a term. Some authors, for instance, explicitly promote the use of the term *Palliative Sedation* instead of *Terminal Sedation* because the latter might suggest that the intention of CSD is the termination of life (Morita et al., 2002). The preference for *Palliative Sedation* thus stems from the fact that this term is emotively charged with the suggestion that the alleviation of pain and/or suffering is the object of CSD. The term used to refer to CSD thus already implies its justifiability –for, begging the question, what could be wrong with the alleviation of pain and suffering?

Considering the overall varying content of the definitions, the two most common terms –*Terminal Sedation* and *Palliative Sedation*- are catch-all phrases. For example, some definitions include the withholding of ANH while others do not. The same goes for core elements like 'refractory symptoms' or 'titrating sedatives'. So-called 'persuasive' definitions abound. A characteristic of persuasive definitions is that they pretend to settle normative problems by offering the 'right' definition of a practice, a term, etc. In the case at hand, persuasive definitions point out what CSD 'really' is: e.g. it is not bringing a patient into a deep coma until death through the withholding of artificial feeding and hydration. As de Graeff e.a. argue, the latter actions should be considered as quite another end-of-life decision (de Graeff and Dean, 2007). Others (Quill for instance) argue that because the withdrawing of ANH is part of CSD, the latter is also a form of life-ending (Quill et al., 1997). Still others argue that CSD is by definition only so, if no life-shortening is intended (Rousseau, 2002).

We can conclude that a clear (moral) debate on CSD is seriously hindered by the lack of uniform, neutral terms and definitions for CSD. Probably due to the controversial (and ambiguous) nature of CSD, the debate is profoundly marked by 'charged language', rich in connotations, aiming at realizing agreement in attitude towards CSD.

Five types of justifications are regularly used to justify CSD on a moral basis. However, not all of these five justifications are equally straightforward. Although an ethical evaluation or appraisal of the justifications is beyond the scope of this study, it is important to mention that some justifications are the subject of ethical debates more often than others. The justification 'Proportionality', for example,

seems to attract less controversy when considering the existing ethical literature than the 'Doctrine of Double Effect'. One of the controversial aspects of the Doctrine of Double Effect is that this justification relies on the distinction between intentions (e.g. providing symptom relief) and consequences (e.g. hastening death). Critics of this distinction often argue that intentions are difficult to validate externally and additionally that they may be multilayered, ambiguous, subjective and sometimes even contradictory (Quill, 1997). In this respect, it is remarkable that a hardly controversial justification like 'Proportionality' was found in only a third of the publications where CSD was found to be morally justified, whereas the more controversial 'Doctrine of Double Effect' was used in more than the half of these opinion pieces. This suggests that this (controversial) doctrine still has a prominent role in deontological models. Only the 'Last Resort' justification was detected more often than the 'Doctrine of Double Effect' which supports the hypothesis that CSD is by and large considered justified only as a last resort therapy. It is also interesting to note that the justifications (except in one case) do not address the interests of the patient's relatives, but are limited to the interest of patients and medical personnel. Equally interesting is the relatively low frequency with which matters of patient consent are addressed.

Because decisions on CSD often involve decisions on ANH, especially when a patient has been rendered completely unconscious, it is striking that issues on ANH remain largely unmentioned when CSD is found to be morally justified. Nonetheless, the withholding or withdrawing of ANH may place CSD in a completely different ethical perspective. The 'Doctrine of Double Effect', for example, cannot be invoked to justify the withholding or withdrawing of ANH (Orentlicher, 1997). For some, the combination of CSD with the withholding of ANH makes it equivalent to life-ending acts. In this content analysis, only a few publications were found that proposed distinct and separate justifications for the withholding of ANH.

In conclusion, the debate over CSD in the opinion sections of medical and nursing journals lacks uniform terms and definitions, and is profoundly marked by 'charged language', aiming at realizing agreement in attitude towards CSD. Not all of the moral justifications found are equally straightforward. To enable a more effective debate, the terms, definitions and justifications for CSD need to be further clarified.

APPENDIX: Search Filters Used

CINAHL

(((MH "Hospice and Palliative Nursing")OR("hospice and palliative nursing")OR(MH "Palliative Care")OR("palliative care")OR(MH "Hospice Care")OR("hospice care")OR(MH "Terminal Care+")OR("terminal care")OR(MH "Terminally Ill Patients")OR("Terminally Ill Patients")OR(MH "Critical Illness")OR("critical illness")OR(MH "Critically Ill Patients")OR("critically ill patients")OR(MH "Hospices")OR("hospices")OR(MH "Hospice Patients")OR("hospice patients")OR(MH "Hospice and Palliative Nurses Association")OR("hospice and palliative nurses association")OR(MH "National Association for Home Care & Hospice")OR("national association for home care & hospice")OR(MH "Dying Process (Saba CCC)")or(MH "Dying-Death Measures (Saba CCC)")or(MH "Dignified Dying (Iowa NOC)")or(MH "Dying Care (Iowa NIC)")OR("end of life")OR("dying")OR("hospice")OR("palliative treatment")OR("palliative therapy")OR("palliative medicine")OR("hospice program"))AND((MH "Sedation")OR("sedation")OR(MH "Hypnotics and Sedatives")OR(MH "Conscious Sedation")OR("conscious sedation")OR(MH "Narcotics")OR("narcotics")OR("deep sedation")OR("sedatives")OR("hypnotics")OR("controlled sedation")))OR(("terminal sedation")OR("palliative sedation")OR("slow euthanasia"))

PubMed

(("palliative care"[mesh] OR ("care"[All Fields] AND "palliative"[All Fields]) OR "care palliative"[All Fields] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields] OR ("therapy"[All Fields] AND "palliative"[All Fields]) OR "therapy palliative"[All Fields] OR ("palliative"[All Fields] AND "therapy"[All Fields]) OR "palliative therapy"[All Fields] OR ("palliative"[All Fields] AND "treatment"[All Fields]) OR "palliative treatment"[All Fields] OR ("treatment"[All Fields] AND "palliative"[All Fields]) OR "treatment palliative"[All Fields] OR ("palliative"[All Fields] AND "treatments"[All Fields]) OR "palliative treatments"[All Fields] OR ("treatments"[All Fields] AND "palliative"[All Fields]) OR "treatments palliative"[all fields] OR ("palliative"[All Fields] AND "surgery"[All Fields]) OR "palliative surgery"[All Fields] OR ("surgery"[All Fields] AND "palliative"[All Fields]) OR "surgery palliative"[All Fields] OR ("palliative"[All Fields] AND "medicine"[All Fields]) OR "palliative medicine"[All Fields] OR ("medicine"[All Fields] AND "palliative"[All Fields]) OR "medicine palliative"[all fields] OR "terminal care"[mesh] OR ("terminal"[all fields] AND "care"[all fields]) OR "terminal care"[all fields] OR ("Care"[All Fields] AND "Terminal"[All Fields]) OR "Care Terminal"[All Fields] OR "hospice care"[mesh] OR ("care"[All Fields] AND "hospice"[All Fields]) OR "care, hospice"[All Fields] OR ("hospice"[All Fields] AND "care"[All Fields]) OR "hospice care"[All Fields] OR ("hospice"[All Fields] AND "programs"[All Fields]) OR "hospice programs"[All Fields] OR ("programs"[All Fields] AND "hospice"[All Fields]) OR "programs Hospice"[All Fields] OR ("hospice"[All Fields] AND "program"[All Fields]) OR "hospice program"[All Fields] OR ("program"[All Fields] AND "hospice"[All Fields]) OR "program hospice"[All Fields] OR ("bereavement"[All Fields] AND "care"[All Fields]) OR "bereavement care"[All Fields] OR ("care"[All Fields] AND "bereavement"[All Fields]) OR "care bereavement"[All Fields] OR "critical illness"[mesh] OR ("critical"[All Fields] AND "illness"[All Fields]) OR "critical illness"[All Fields] OR ("illness"[All Fields] AND "critical"[All Fields]) OR "illness critical"[All Fields] OR ("critical"[All Fields] AND "illnesses"[All Fields]) OR "critical illnesses"[All Fields] OR ("illnesses"[All Fields] AND "critical"[All Fields]) OR ("critically"[All Fields] AND "ill"[All Fields]) OR "critically ill"[All Fields] OR ("Ill"[All Fields] AND "Critically"[All Fields]) OR "terminally ill"[mesh] OR ("terminally"[All Fields] AND "ill"[All Fields]) OR "terminally ill"[All Fields] OR ("ill"[All Fields] AND "terminally"[All Fields]) OR "hospices"[mesh] OR "hospices"[All Fields] OR "hospice"[All Fields] OR "end of life"[All Fields] OR "dying"[All Fields]) AND ("conscious sedation"[mesh] OR ("conscious"[All Fields] AND "sedation"[All Fields]) OR "conscious sedation"[All Fields] OR ("sedation"[All Fields] AND "conscious"[All Fields]) OR "sedation conscious"[All Fields] OR ("sedation"[All Fields] AND "moderate"[All Fields]) OR ("moderate"[All Fields] AND "sedation"[All Fields]) OR "moderate sedation"[All Fields] OR "deep sedation"[mesh] OR ("deep"[All Fields] AND "sedation"[All Fields]) OR "deep sedation"[All Fields] OR ("sedation"[All Fields] AND "deep"[All Fields]) OR "sedation, deep"[All Fields] OR ("deep"[All Fields] AND "sedations"[All Fields]) OR "deep sedations"[All Fields] OR ("sedations"[All Fields] AND "deep"[All Fields]) OR "hypnotics and sedatives"[mesh] OR ("hypnotics"[All Fields] AND "sedatives"[All Fields]) OR "hypnotics and sedatives"[All Fields] OR ("sedatives"[All Fields] AND "hypnotics"[All Fields]) OR "sedatives and hypnotics "[All Fields] OR "sedatives"[All Fields] OR "Hypnotics"[All Fields] OR "Narcotics"[All Fields] OR ("controlled"[All Fields] AND "sedation"[All Fields]) OR "controlled sedation"[All Fields] OR ("Sedation"[All Fields] AND "Controlled"[All Fields]) OR "sedation controlled"[All Fields])) OR (("terminal"[All Fields] AND "sedation"[All Fields]) OR "terminal sedation"[All Fields] OR ("sedation"[All Fields] AND "terminal"[All Fields]) OR ("Palliative"[All Fields] AND "Sedation"[All Fields]) OR "palliative sedation"[All Fields] OR ("Sedation"[All Fields] AND "Palliative"[All Fields]) OR ("slow"[All Fields] AND "euthanasia"[All Fields]) OR "slow euthanasia"[All Fields] OR ("euthanasia"[All Fields] AND "slow"[All Fields])) AND ("humans"[MeSH Terms] AND (Editorial[ptyp] OR Letter[ptyp] OR Comment[ptyp]) AND English[lang])

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REFERENCES

Baumrucker, S.J. 2002. Sedation, dehydration, and ethical uncertainty. *American Journal of Hospice and Palliative Care* 19: 299-300.

Billings, J.A. and Block, S.D. 1996. Slow euthanasia. *The Journal of Palliative Care* 12: 21-30.

Braun, T.C., Hagen, N.A., and Clark, T. 2003. Development of a clinical practice guideline for palliative sedation. *Journal of Palliative Medicine* 6: 345-350.

Broeckaert, B., Mullie, A., Gielen, J., Desmet, M., Vanden Berghe, P. and Stuurgroep Ethiek FPZV [Ethics Commission Federation Palliative Care Flanders]. 2010. Richtlijn palliatieve sedatie [Palliative Sedation Guideline]. http://www.pallialine.be/template.asp?f=rl_sedatie.htm#page=page-1. Accessed 2 February 2011.

Chambaere, K., Bilsen, J., Cohen, J., Rietjens, J.A., Onwuteaka-Philipsen, B.D., Mortier, F. and Deliens, L. 2010. Continuous deep sedation until death in Belgium: a nationwide survey. *Archives of Internal Medicine* 170: 490-493.

Cherny, N.I. and Radbruch, L. 2009. European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. *Palliative Medicine* 23: 581-593.

Claessens, P., Menten J., Schotsmans, P. and Broeckaert, B. 2008. Palliative sedation: a review of the research literature. *Journal of Pain and Symptom Management* 36: 310-333.

Committee on National Guideline for Palliative Sedation, Royal Dutch Medical Association (KNMG). 2009. *Guideline for palliative sedation*. Utrecht: Royal Dutch Medical Association. http://knmg.artsennet.nl/web/file?uuid=f3e026ba-23ec-47f1-a698-212153427fd7&owner=a8a9ce0e-f42b-47a5-960e-be08025b7b04&contentid=37350. Accessed 29 February 2012.

Council on Ethical and Judicial Affairs. 2008. Sedation to unconsciousness in end-of-life care. CEJA Report 5-A-08. http://www.ama-assn.org/ama1/pub/upload/mm/code-medical-ethics/2201a.pdf Accessed 17 April 2012.

de Graeff, A. and Dean, M. 2007. Palliative sedation therapy in the last weeks of life: a literature review and recommendations for standards. *Journal of Palliative Medicine* 10: 67-85.

Hawryluck, L.A., Harvey, W.R., Lemieux-Charles, L., and Singer, P.A. 2002. Consensus guidelines on analgesia and sedation in dying intensive care unit patients. *BMC Medical Ethics* 3: E3.

Hermsen, M.A. and ten Have, H.A. 2001. Moral problems in palliative care journals. *Palliative Medicine* 15: 425-431.

Kirk, T.W. and Mahon, M.M. 2010. National Hospice and Palliative Care Organization (NHPCO) position statement and commentary on the use of palliative sedation in imminently dying terminally ill patients. *Journal of Pain and Symptom Management* 39: 914-923.

Lynn, J. 1998. Terminal sedation. *The New England Journal of Medicine* 338: 1230-1231.

Miccinesi, G., Rietjens, J.A., Deliens, L., Paci, E., Bosshard, G., Nilstun, T., Norup, M. and van der Wal, G. 2006. Continuous deep sedation: physicians' experiences in six European countries. *Journal of Pain and Symptom Management* 31: 122-129.

Morita, T., Tsuneto, S. and Shima, Y. 2002. Definition of sedation for symptom relief: a systematic literature review and a proposal of operational criteria. *Journal of Pain and Symptom Management* 24: 447-453.

Morita, T., Bito, S., Kurihara, Y. and Uchitomi, Y. 2005. Development of a clinical guideline for palliative sedation therapy using the Delphi method. *Journal of Palliative Medicine* 8: 716-729.

Mount, B. 1996. Morphine drips, terminal sedation, and slow euthanasia: definitions and facts, not anecdotes. *The Journal of Palliative Care* 12: 31-37.

National Ethics Committee, Veterans Health Administration. 2006. The ethics of palliative sedation as a therapy of last resort. *American Journal of Hospice and Palliative Care* 23: 483-491.

Orentlicher, D. The Supreme Court and physician-assisted suicide--rejecting assisted suicide but embracing euthanasia. 1997. *The New England Journal of Medicine* 337:1236-123.

Quill, T.E., Lo, B. and Brock, D.W. 1997. Palliative options of last resort: a comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. *The Journal of the American Medical Association* 278: 2099-2104.

Quill, T.E. 1993. The ambiguity of clinical intentions. *The New England Journal of Medicine*. 329 (14): 1039-1040.

Rietjens, J.A., van der Heide, A., Vrakking, A.M., Onwuteaka-Philipsen, B.D., van der Maas, P.J., and van der Wal, G. 2004. Physician reports of terminal sedation without hydration or nutrition for patients nearing death in the Netherlands. *Annals of Internal Medicine* 141: 178-185.

Rietjens, J.A., van Delden, J., Onwuteaka-Philipsen, B.D., Buiting, H., van der Maas, P. and van der Heide, A. 2008. Continuous deep sedation for patients nearing death in the Netherlands: descriptive study. *British Medical Journal* 336: 810-813.

Rousseau, P. 2002. Careful conversation about care at the end of life. *Annals of Internal Medicine* 137: 1008-1010.

Rousseau, P.C. 2006. Palliative sedation and the fear of legal ramifications. *Journal of Palliative Medicine* 9: 246-247.

Stevenson, C.L. 1969. *Ethics and Language*. London: Yale University Press.

Strauss, A., and Corbin, J. 1990. *Basics of qualitative research: Grounded theory procedures and techniques.* London: Sage.

Swart, S.J., Brinkkemper, T., Rietjens, J.A., Blanker, M.H., van Zuylen, L., Ribbe, M., Zuurmond, W.W., van der Heide, A. and Perez R.S. 2010. Physicians' and nurses' experiences with continuous palliative sedation in the Netherlands. *Archives of Internal Medicine* 170: 1271-1274.

Thorns, A. 2002. Sedation, the doctrine of double effect and the end of life. *International Journal of Palliative Nursing* 8: 341-343.

Van Deijck, R.H., Krijnsen, P.J., Hasselaar, J. G., Verhagen, S.C., Vissers, K.C., and Koopmans, R.T. 2010. The practice of continuous palliative sedation in elderly patients: a nationwide explorative

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study among Dutch nursing home physicians. *Journal of the American Geriatrics Society* 58: 1671-1678.

van Delden, J.J. 2007. Terminal sedation: source of a restless ethical debate. *Journal of Medical Ethics* 33: 187-188.

Ventafridda, V., Ripamonti, C., De Conno, F., Tamburini, M., Cassileth, B.R. 1990. Symptom prevalence and control during cancer patients' last days of life. *The Journal of Palliative Care 6*: 7-11.

Wein, S. 2000. Sedation in the imminently dying patient. *Oncology (Williston.Park)* 14: 585-592.

Zylicz, Z. 2004. Terminal sedation in the Netherlands. *Annals of Internal Medicine* 141: 966-967.

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Table 1: General Characteristics of Opinion Pieces on Continuous Sedation until Death (n=89)

		Frequency (n)	Percent
Publication type	Comment or letter from reader	72	80.9
	Editoral	17	19.1
Type of journal	Palliative (10)	36	40.4
(number of different journals)	General & internal medicine (8)	34	38.2
	Bioethical (4)	6	6.7
	Other (9)	13	14.6
Professional background first author	Physician (55)	68	76.4
(number of different authors)	Nurse (9)	10	11.2
	Ethicist or philosopher (4)	4	4.5
	Other (6)	6	6.7
	Unknown (1)	1	1.1
Country first author	North America	58	65.2
	USA	53	59.6
	Canada	5	5.6
	Europe	20	22.5
	UK	11	12.4
	the Netherlands	6	6.7
	Italy	1	1.1
	France	1	1.1
	Portugal	1	1.1
	Other	11	12.4
	Israel	3	3.4
	Japan	3	3.4
	Australia	2	2.2
	New Zealand	1	1.1
	Singapore	1	1.1
	South Africa	1	1.1
Definition of CSD* given		17	19.1
Moral justification for CSD given		65	73
Total		89	100

* CSD: Continuous Sedation until Death. Definitions of CSD are seen as distinct text passages describing specifically the meaning of the respective term used for CSD.

Table 2: Terms Used for Continuous Sedation until Death by Year of Publication (n=89)

	Year of publication																	
Term used for CSD*	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Total
Terminal Sedation	-	-	-	2	-	8	-	6	1	4	2	3	5	-	2	4	1	38
Palliative Sedation	-	-	-	-	-	-	-	1	2	7	2	-	3	4	2	2	4	27
Sedation	1	-	-	2	-	-	-	-	-	2	1	1	-	1	-	2	1	11
Slow Euthanasia	-	-	-	3	1	-	-	-	1	-	-	-	-	-	-	-	-	5
Sedation in the Imminently Dying (SID)	-	-	-	-	-	-	-	4	-	-	-	-	-	-	-	-	-	4
Other	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-	1	2	4
No. opinion pieces on CSD	1	-	-	7	1	8	-	12	4	13	5	4	8	5	4	9	8	89

* CSD: Continuous Sedation until Death

Table 3: Terms Used in Relation to the Core Elements of Their Definition (n=17)

	Terms used, accompanied with a definition				
Core elements of the respective definition*	Terminal Sedation % (n=9)	Palliative Sedation % (n=6)	Sedation % (n=1)	Slow Euthanasia % (n=1)	Total % (n=17)
Removing consciousness	44.4 (4)	33.3 (2)	- -	100 (1)	41.2 (7)
Refractory symptoms	22.2 (2)	66.7 (4)	- -	- -	35.3 (6)
Lowering consciousness by titrating sedatives	22.2 (2)	33.3 (2)	100 (1)	- -	29.4 (5)
Until death	33.3 (3)	- -	- -	- -	17.6 (3)
Intention is symptom control, not causing death	11.1 (1)	33.3 (2)	- -	- -	17.6 (3)
ANH† are withheld	33.3 (3)	- -	- -	- -	17.6 (3)
At the end of life/for dying patients	22.2 (2)	- -	- -	- -	11.8 (2)

* Multiple elements possible per definition/term. Definitions of Continuous Sedation until Death (CSD) are seen as distinct text passages describing specifically the meaning of the respective term used for CSD.
† Artificial Nutrition and Hydration

Box 1: Inductive Coding Framework of Moral Justifications for Continuous Sedation until Death (CSD)

Label	General explanation	Text indicators (terms, modes or conditions of conduct, ...)	Text examples
Last Resort	All forms of 'last resort reasoning' fall under this type of justification.	Last resort reasoning: administering CSD not until there are unbearable refractory symptoms. The possibility for a physician to administer CSD on his own initiative, for example in acute situations such as suffocation, massive bleeding etc.	*"Terminal sedation is not ordinarily the choice of an awake and thoughtful person. Rather, it is usually instituted after trials of reduced dosages, alternative medications, or adjuvant medications fail to provide adequate pain management."*(Lynn, 1998)
Doctrine of Double Effect (DDE)	The DDE is broadly conceived within this study, without a strict interpretation of the four traditional conditions for its application. DDE is perceived in this study when it is assumed that CSD causes a double effect: an intended effect and a merely foreseen one. For example symptom control and removing consciousness, or symptom control and life shortening. The intended effect must outweigh the foreseen, but not intended, side effect.	Harmful effects, such as life shortening or the diminishment or suppression of consciousness, may be foreseen but not intended. The control of symptoms must be the only intention. DDE When the physicians' intention is emphasized in the text (and thus two possible effects are implicitly presumed to possibly occur).	*"Sedation provides a means of alleviating this distress but with risks that may be justified by the DDE. The intention behind the sedation is good: to relieve distress, not to bring about the patient's death."*(Thorns, 2002)
Sanctity of Life	The core of the principle of the Sanctity of Life is the absolute prohibition of intentionally killing (innocent) life. Within this study, this justification is interpreted in the way that a patient may only die because of the underlying disease, not as a consequence of the administration of CSD.	Never combine CSD with the withholding of ANH ANH may only be withheld or withdrawn when patients are in their dying phase or when they have a life expectancy of less than two weeks. In other words: no risk on life shortening by withholding ANH may be taken. ANH may be withheld when the patient has already stopped eating and drinking before being sedated. The presupposition that CSD is not life shortening. When a lack of difference in survival between sedated and non-sedated patients is being claimed. The artificial coma must be reversible.	*"While the fear of hastening death is a reasonable concern for clinicians, a small amount of literature suggests that terminally ill sedated patients do not die sooner than a similar cohort of terminally ill non-sedated patients."*(Rousseau, 2006) *"Unless death is imminent and unavoidable, sedation without hydration does violate the principle of double effect, …"*(Baumrucker, 2002)

Box 1: Continued

Label	General explanation	Text indicators (terms, modes or conditions of conduct, ...)	Text examples
Autonomy	The informed consent of the patient, as a dictated condition to administer CSD, forms the core of this justification.	Informed consent: a competent and adequately informed patient consenting to CSD In case of an incompetent patient: the assumption that the patient would consent to CSD, based on earlier conversations or an advance directive. Also the so-called surrogate decisions fall under this label. (the right to) Self-determination	*"Before instituting any intervention aimed at relieving refractory symptoms, it is crucial to involve the patient or surrogate in informed decision-making."*(Wein, 2000)
Proportionality	This justification requires that the risk of causing harm is directly related to the gravity and urgency of a patient's clinical situation and the expected benefit of the intervention.	The titration of sedatives, the depth of sedation must be in reasonable proportion to the burden of symptom, not heavier than necessary, etc. The greater the suffering, the greater the risk (e.g. on shortening life) that may be taken to control symptoms.	*"The dose of sedating drugs is titrated upward until the patient is peaceful."*(Zylicz, 2004)
Other justifications		e.g. managing CSD is less burdensome for the physician than managing other means of symptom control e.g. administering CSD to meet the requests of the family (because the dying process is too burdensome for them)	

Table 4: Found Moral Justifications for Continuous Sedation until Death (n=65)

	Withholding/withdrawing of ANH included? †							
	no ‡		yes		unknown		Total	
Justification *	%	(n=9)	%	(n=14)	%	(n=42)	%	(n=65)
Last Resort	13.8	(9)	15.4	(10)	46.2	(30)	75.4	(49)
Doctrine of Double Effect	10.8	(7)	6.2	(4)	35.4	(23)	52.3	(34)
Sanctity of Life	9.2	(6)	12.3	(8)	12.3	(8)	33.8	(22)
Autonomy	9.2	(6)	1.5	(1)	21.5	(14)	32.3	(21)
Proportionality	10.8	(7)	4.6	(3)	16.9	(11)	32.3	(21)
Other	-	-	-	-	3.1	(2)	3.1	(2)

* More than one justification per publication possible
† ANH: artificial nutrition and/or hydration
‡ In 5 of these publications we found distinct justifications for the withholding of ANH